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THE UNIVERSITY OF ALBERTA

PARENTING A VISUALLY IMPAIRED CHILD: THE MOTHER'S PERSPECTIVE

by

KIMBERLY DOUGLAS HANCOCK

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND

RESEARCH IN PARTIAL FULFULMENT OF THE REQUIREMENTS

FOR THE DEGREE OF MASTER OF EDUCATION

IN SPECIAL EDUCATION

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

SPRING, 1988

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ISBN 0-315-42795-7

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Degree: Master of Education

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, this thesis entitled:

Parenting a Visually Impaired Child:

A Mother's Perspective

Submitted by: Kimberly Douglas Hancock

in partial fulfilment of the requirements for the degree of Master of Education, in Special Education.

L. Walsh.....

Linda McDonald

Charles A. Norman

John Swan.....

Date: December 18, 1987

Abstract

The purpose of this study was to document, understand, and learn from the experiences of mothers with visually impaired children. To better understand the personal experiences of these mothers, a semi-structured, open-ended interview session was conducted. Six mothers of visually impaired children participated in this study. There were three dominant themes which emerged from data analysis conducted on the written protocols of the mothers interview sessions: (1) Emotional Issues, (2) Coping Strategies, and (3) Problems and Concerns. Within these three dominant themes were supporting sub-themes which described the phenomemon of the dominant theme. The first dominant theme, emotional issues, did not have any sub-themes. The second dominant theme concerned coping strategies. The sub-themes were: (2a) personality; (2b) child's attitude; (2c) accomplishments; and (2d) support networks. The third dominant theme was problems and concerns. The subsequent sub-themes were: (3a) professionals; (3b) education; (3c) people's attitudes; and (3d) time involvement.

Implications of the study were reviewed and suggestions for future research in support networks, parent-professional relationships, and education were made.

Acknowledgements

I would like to acknowledge the following individuals for their support and assistance througout this project.

- the mothers, who participated in this study, for their honesty and willingness to share their experiences.

- David, for his encouragement and patience during the completion of this degree. And, to his family, who have also been very supportive.

-my parents, who have endorsed my abilities from the start, and in many ways, fostered the best in me. I thank them for their love.

-my co-supervisors, Dr. L. McDonald, and Dr. L. Wilgosh, and committee members, Dr. C. Norman, and Dr. R. Ware, for their guidance, suggestions, and assistance throughout this project.

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Chapter I

Introduction

The birth of a child is a joyful and eagerly awaited moment. Parents often fantasize about their unborn child, and place high expectations upon the newborn's arrival. During pregnancy, the mother might also worry that her infant will be handicapped. These passing thoughts, however, are in no way a preparation for the birth of an exceptional child (Mercer, 1984; Poznanski, 1974). The expectation of a normal child is shattered when parents are told their child is handicapped. Overwhelmed by feelings of anger, shock, confusion or disappointment, the parents may view the birth of a handicapped child as the death of an expected normal child (Bristor, 1984; Seligman, 1985).

> It's worse in some ways than the death of a normal child because you gradually realize that this child is never going to live in the fullest sense of the word. It is only after months or years pass that you find out how your family will be affected. (Garguiolo, 1985, p. 78)

Certainly not every handicap occurs at birth. Diagnosis of a handicap can occur at any time during the child's life. Factors affecting the time of diagnosis include the degree and nature of the handicap, the competence of the attending physician, and the family history and dynamics (Vernon, 1979). The official

diagnosis is often the beginning of the family crisis. Whether diagnosis occurs at birth, or at a later age, parents of handicapped children display similar reactions (Berry & Zimmerman, 1983; Gallagher, Buckman, & Cross, 1983; Mori, 1983; Poznanski, 1984). Although parents of exceptional children are not a homogeneous group, research indicates emerging patterns in the emotional experiences of these special parents (Blacher, 1984; MacKeith, 1973; Mori, 1983; Opirhory & Peters, 1982; Poznanski, 1984; Seligman, 1985; Swick, 1984). One shared experience concerns the education of the exceptional child.

As a result of the passage of Public Law 94-142 in the United States in 1974, families are encouraged to raise their handicapped child at home, become involved in their child's educational program, and mainstream their child into a local school setting. This law, which mandated appropriate programming for special needs individuals, provided a precedent for North American professionals involved with special education. Issues concerning traditional programs heightened the concern of Canadian, as well as American professionals.

In Canada, there is no ministry at the federal level which initiates funding and legislation to ensure equal education for exceptional students (Bachor & Crealock,

1986). The federal ministry does, however, support and fund programs, and contribute to research into special education. There are six provinces (Newfoundland, Nova Scotia, Quebec, Ontario, Manitoba and Saskatchewan) which provide mandated programs, and the remaining four provinces, the Northwest Territories and Yukon, have permissive legislation (Bachor & Crealock, 1986). The provinces which mandate legislation request agencies involved with families to use an appropriate model program, allocate resources, and involve parents in program planning (Bachor & Crealock, 1986). Parental involvement, with their exceptional child's education, has lead to increased studies concerning the family's involvement with the special needs child (Fewell, 1986; Garguiolo, 1985; and Seligman, 1985).

The proposed Bill 59, currently under consideration in Alberta, contains an educability clause which states that schools have the right to refuse service to any child they feel is "un-educable." According to Sobsey (1987), however, the law does not clearly define who determines the child's ability or non-ability to be educated. While parents of a single sensory handicap, (e.g. visual impairment) may not feel this law has implications for their children, Sobsey (1987) warns otherwise.

The withdrawal of a basic public service from

> any group of individuals on the basis of a disability sets a precedent that may affect every individual with handicaps. The same logic which allows the exclusion of education on the basis of "non-educability" allows excluding the "non-transportable" from public transportation, and so on. This legislation represents a giant step backwards for every Albertan with a disability (Sobsey, 1987, p. 3).

It appears that under this newly proposed law, education in Alberta will no longer be considered a right, but a privilege for those who are deemed "educable" (Sobsey, 1987). Instead of progressing in the area of education for the handicapped, Alberta education may be regressing. Education is not the only area in which parents are being encouraged to become a more active partner. Parents with exceptional children are often involved with many different agencies concerning the needs of their special child.

Parents of handicapped children in the 1980's are still faced with agencies which direct their services towards the child, in isolation, without providing support networks for the family. Often these parents become disheartened with the agency. Professionals, in turn, may feel a sense of helplessness as they are faced

with insufficient knowledge and understanding of families with exceptional children (Bennett, 1986; Bristor, 1984; Gallagher, et al., 1983; McClure & Lindsey, 1984; Poznanski, 1984; Waisbren, 1980).

To date there is little information concerning parental experiences of raising handicapped children other than those parents of the mentally handicapped (Blacher, 1984; Bristor, 1984; McClure & Lindsey, 1984; Poznanski, 1984; Seligman, 1985; Van Hasselt, Hersen, Moor, & Simon, 1986). Seligman (1985) cited "the study of families with children other than mental retardation is a most needed contribution" (p. 275). Because of the low incidence of visual impairments, and lack of research conducted with their families, there is sparce information concerning emotional experiences of parents with visually impaired children (Van Hasselt, et al., 1986). Therefore, the following literature review discusses research which involved observing families with children having various handicapping conditions.

Definition of Terms

VISUAL IMPAIRMENT - for the purpose of this study, any child who was registered with the Canadian National Institute for the Blind, in Edmonton, Alberta, was considered visually impaired. The CNIB only registers those individuals with a visual acuity score of 20/200 or

greater, or those individuals with a visual field loss. There was no identification of the individual's type and degree of visual loss in this study, due to protecting the confidentiality of the participants.

STRESS - a set of circumstances that requires the parent to change their life patterns. The circumstances or events are considered crisis-provoking and for which the family has little or no preparation.

COPING - the parents ability to deal with problems, troubles and conflicts as they arise.

DOMINANT THEME - refers to the three major themes which emerged from the semi-structured, open-ended interview questions. Dominant themes were identified through the direction of the interview question, and when the participants discussed four or five situations (sub-themes) while raising their visually impaired child.

SUB-THEMES - were the various situations or experiences, which evoked similar behaviours or reactions, that made up the three dominant themes. For example, the sub-themes of professionals, education, people's attitudes, and time involvement were components of the dominant theme "problems and concerns".

Chapter II

Review of the Literature

The purpose of this research is to document emotional issues of raising a visually impaired child. Topics such as sources of stress, emotional responses to the stress, maternal coping behaviours, and the use of grounded-theory in research will be discussed in the following sections.

Families with Special Needs Children

It is not surprising that research indicates caring for an exceptional child is much more demanding than caring for the "usual" child (Beckman, 1983; Beckman-Bell, 1981; Bennett, 1986; Fewell, 1986; Fotheringham & Creal, 1974; Fortier & Wanlass, 1984; Gallagher, et al., 1983; Harvey & Greenway, 1982; Longo & Bond, 1984; Paul, 1981; Poznanski, 1984). Families with handicapped children appear to experience additional stress and crises, while dealing with ongoing, highly complex situations. In addition to problems arising from the handicapping condition, these families experience daily life difficulties as do families with non-handicapped members. It is important to note, however, that families with a handicapped child are not necessarily "handicapped" families.

In research conducted by Longo & Bond (1984), positive interactions with families successfully parenting their exceptional child were observed.

> It was enlightening but nonetheless puzzling to interact with families who did not appear to be in crisis or grief stricken, but rather caught up in the daily struggle of meeting the challenge they faced". (p. 57)

Professionals should be cautioned, when assessing families with handicapped children, not to anticipate familial chaos, or maladjustment. Research indicates there are families who adjust to, and cope with their child's handicapping condition (Ferguson & Watt, 1980; Garguiolo, 1985; Harvey & Greenway, 1982; Kazak & Marvin, 1984; Longo & Bond, 1984; Seligman, 1985). Nonetheless, there are few research articles written on positive outcomes of parenting a handicapped child (Blacher, 1984).

Perhaps families are best understood when observed as a wholistic unit. "Family members do not operate in a vacuum. Members are influenced and changed by other members, and by the circumstances in which they exist" (Fewell, 1986; p. 4). It is important to understand each family's ecosystem, in order to understand it's needs. Turnbull & Turnbull (1986) refer to this as the Family Systems Theory, the basic premise being "that the individual members of a family are so interrelated that any experience affecting one member will affect all" (p. 18). For example, the mother may become so involved with

the care-taking needs of the exceptional child, the other siblings are neglected.

It is imperative, however, that investigators realize that each family member plays a different role in the network (Opirhory & Peters, 1982). According to Berry & Zimmerman (1983), there are justifiable reasons for focusing a study on one individual's experience with the handicapped child. "Each member of a parental pair is different, and the two are quite likely to be at different stages at any given time"(Berry & Zimmerman, 1983; p. 227). In order to assist families with handicapped children we must understand the influences that each member and his/her environment have on one another (Fewell, 1986; Fotheringham & Creal, 1974). Each family member may react and deal with situations in different and unique ways; just as their reactions are different, so are the perceptions of their experiences.

This study will focus primarily on the maternal aspect of parenting a visually impaired child. This is not to suggest, however, that the views of other family members are not important. In the following section, the topic of mothers with exceptional children will be discussed.

Mothers of Exceptional Children

Owing to the increased emotional attachment

following nine months of pregnancy, mother's display different emotional reactions towards their child than the father (Bristor, 1984). Not only are their emotional experiences different, the parents perform quite diverse and distinct roles within the family (Fewell, 1986; Kazak & Marvin, 1984; Paul, 1981; Turnbull & Turnbull, 1986). The added responsibility of caring for the child increases stress in mothers moreso than fathers (Fewell, 1986; Kazak & Marvin, 1984; Longo & Bond, 1984; Seligman, 1985). To support this statement, researchers have investigated the role parents assume while raising the exceptional child. Mothers were found to be the initial and on-going care-giver. They also spend more time with their child and conducted the majority of child related chores than did the fathers (Dunst, Trivette, & Cross, 1986; Fewell, 1986; Hardman, Drew, & Egan, 1984; Kazak & Marvin, 1984). Madiros (1985) contends that gender identity and role-relevant traits are acquired through social and learning processes. According to Madiros, (1985), one reason mothers tend to be the initial and on-going care-giver is because females "continue to be socialized towards nurturance, social orientation, attachment behaviours, and dependency." (p. 25).

Much of the research concerning families with a handicapped child has observed traditional families.

Studies of non-traditional families (single parent homes, extended families, and step families) have become more prevalent (Fewell, 1986; Kazak & Marvin, 1984; Turnbull & Turnbull, 1986). On the increase also, are studies concerning fathers', grandparents',and siblings' adaptation to having a special needs individual in the family (Seligman, 1985).

While the female parent assumes the role of mother and becomes absorbed in domestic activities, her primary focus is her children and home. This involvement often creates loneliness and isolation for the parent. Mothers who have previously been active in the community and workplace may find themselves virtually cut off from society.

Maternal roles with the exceptional child vary in function as the child and mother grow older. As the child's age and needs progress, the mother finds herself in new situations (Fewell, 1986; Hardman, Drew, & Egan, 1986). Her handicapped child may become more difficult to manage and care for as he/she matures (Gallagher, et al., 1983). The child's developing maturity may remind the mother of her own vulnerability. She is reminded how "little control we have over our destiny and of the fragile nature of human life itself" (Mori, 1983; p. 23). It is important to remember while investigating a mother-

child dyad that a mother is "more than the sum of the experiences she has had because of her child" (Madiros, 1985, p. 26).

Because mothers of exceptional children are the primary care-givers, and appear most vunerable to the demands of parenting, the focus of this study is on them. The sources of stress, pertaining to raising exceptional children, will be discussed next.

Sources of Stress

Definitions of stress, as they will be applied to this study, have been taken from literature on families with handicapped children. Beckman-Bell (1981) refers to stress as a "set of circumstances that require change in the individual's ongoing life pattern" (p. 46). According to Gallagher, Beckman, & Cross, (1983) stress is defined as a "crisis-provoking event or situation for which the family has little or no preparation" (p. 11). In keeping with these definitions, it is not suprising that families with an exceptional child are subject to additional stress, more than families with a typical child (Beckman-Bell, 1981; Deluca & Salerno, 1984; Fortier & Wanlass, 1984; Gallagher, et al., 1983; Harvey & Greenway, 1982; Kazak & Marvin, 1984; Seligman, 1985; Waisbren, 1980).

Stress emanates from a multitude of sources in the family's environment. Some of these sources are

unalterable characteristics over which professionals have no control. Such variables are the family's socio-economic status, personalities, past experiences, occupations, number of siblings, and the child's handicapping condition (Blacher, 1984; Gallagher, et al., 1983; Paul, 1981; Poznanski, 1984). There is considerable controversy, however, concerning variables affecting stress. For example, Gallagher, Beckman & Cross, (1983), reference studies which have concluded there is a difference in stress levels of parents with children of various diagnostic categories of handicaps. Longo & Bond (1984), however, selectively cited studies which concluded that various handicapping conditions do not necessarily correlate with higher stress levels in parents. Other variables, with which controversial results have been obtained, are marital happiness, degree of impairment, socio-economic status, and number of support networks. Other child related variables which may affect family stress and coping include: child gender (Bristol, 1979); severity of the handicapping condition (Bradshaw & Lawton, 1978); age of the child (Blacher, 1984); and child's personality characteristics (Bristol,1979).

Whether these variables are the indices of stress depends on the family network. Stress may be caused by only one of these variables, or it may be an aggregate of

two or more variables.

One alterable variable, cited in the literature, is stress caused during parent-professional interaction. Difficulties between the two groups have been revealed as a source of stress for parents (De Luca & Salerno, 1984; Gallagher, et al., 1983; Hardman, Drew, & Egan, 1984; McClure & Lindsy, 1984; Paul, 1981; Seligman, 1985; Turnbull & Turnbull, 1986).

The quality of and rapport within the parent-professional partnership is a crucial factor in providing the best suitable programming for the exceptional child. When this relationship is successful, it can be rewarding and satisfying for parent and professional alike (Schulz, 1981). However, some researchers describe the literature pertaining to the parent-professional partnership as being counterproductive and gloomy (Garguiolo, 1985; Gallagher, et al., 1983).

Whenever two or more groups are asked to join forces and cooperate, conflict can arise. Interactions between parents and professionals are no exception. In general, parents may feel the professional does not understand their situation, and professionals may believe the parent is uncaring or overprotective (Garguiolo, 1985; Lipsky, 1985; Turnbull & Turnbull, 1986). Heward, Dardig, and Rossett (1979) indicated that professionals perceive

parents as often avoiding professional contact, as hostile, uncooperative, and uninterested. Parents, in turn, perceive professionals to be negative, unavailable, and condescending. Professionals may appear to be condescending to parents, as the professional tends to take an authoritative role in the life of families with handicapped children (Moeller, 1983; Schulz, 1981). The professional may treat the parents as potential patients needing treatment, rather than experts in their own roles as care-providers (Fewell, 1986). It is important to note, however, not all parent-professional partnerships are negative experiences. Believing that may cause parents and professionals to enter into a partnership with defensive preconceived notions, and defensive attitudes. Moeller (1986), a parent of an exceptional child, has described her feelings about professionals. "We can relax in their presence; they are safe people, whereas contacts with others outside the immediate family circle are often uncomfortable and occasion for anxiety or embarrassment" (p. 165).

A successful parent-professional partnership is important to the development of appropriate programs for the child. No other person knows the child as well as the parents do. "There experiences predate and exceed that of any professional" (Garguiolo, 1985, p. 5). Parents offer

unique and insightful suggestions concerning their child. Professionals, in turn, can provide direction and support for the parents. The two groups, in partnership, provide a "greater understanding of the overall needs of the child" (Heward, Dardig, & Rossett, 1979). The receiving and sharing of information concerning the child benefits the parents, professionals, and especially the child. "While parents have individual ways of adjusting to life with a handicapped child, they all have one thing in common: They all want to find the most appropriate services for their special needs child" (Moeller, 1986, p. 158). Successful parent-professional relationships are beneficial to the parent, as well as the child, and appear to be an alterable variable that professionals need to address.

While raising an exceptional child, parents may experience various emotional responses to the stressful conditions. Several of these emotional reactions are discussed in the following section.

Emotional Responses to Stress

As previously discussed, mothers of special needs children are particularly vulnerable to stress. Their reactions to stress can be both helpful and harmful. Although care-giving chores are demanding, they necessitate involvement from the mother, which is, in

turn, beneficial to her and the child. Instead of remaining in a state of depression following diagnosis, the mother must concern herself with the child's needs (Mercer, 1974). However, stress-related emotions are harmful when they cause lowered self-esteem, frustration, physical exhaustion, and maternal aggression (Blacher, 1984; Fewell, 1986; Mercer, 1974).

An individual's responses to stressful situations are manifested through psychological and/or physical reactions. The psychological responses are displayed through emotional reactions such as depression, anger, grief, shock, denial, or other numerous emotional behaviours. These behaviours not only have emotional implications, but affect the intellectual, physical, biological, behavioural, and spiritual aspects of the family (Bristor, 1984; Fortier & Wanlass, 1984).

Several emotional responses which occur after diagnosis of an exceptional child may serve as a psychic anesthetic (Blacher, 1984; Tuttle, 1986; Vernon, 1979). This "emotional numbness" allows parents to adjust to the crisis, while sorting out their feelings (Berry & Zimmerman, 1983).

The emotional impact following the diagnosis of exceptional needs in a child may elicit certain responses from the parents. Poznanski (1984) and Opirhory & Peters

(1982) stated that overprotection of the child may result from the parents denial of the emotional reactions of anger, guilt, or resentment. Shock and disbelief appear to trigger a "shopping behaviour" in some parents. This occurs when parents disagree with the initial diagnosis and search for a more positive one (Berry & Zimmerman, 1983; Blacher, 1984; Fortier & Wanlass, 1984; MacKeith, 1973; Mori, 1983). Excessive guilt may be associated with depression and anger. These latter emotions may, in turn, bring forth aggression (MacKeith, 1973; Simeonsson & Simeonsson, 1981).

Anger and guilt are the two most frequently reported emotions of parents with handicapped children (Bennett, 1986; Bristor, 1984; Van Hasselt, et al., 1986). These feelings, however, are "normal, reasonable, and necessary parts of adjusting to special parenting tasks" (p. 52). On the other hand, excessive worry, guilt, or anger is neither productive, nor necessary. It is when parents cannot resolve or understand these feelings that difficulties with coping occurs. In its blatant form, denial hinders psychological adaptation and personal management (Ferguson & Watt, 1984; Poznanski, 1984). Unresolved grief becomes a major stressor in the parent's life and may consume energy needed for the care of the child (Bristor, 1984; Tuttle, 1986).

Whether these emotional manifestations occur in a stage-like progression will be discussed next.

Stages of Emotional Reactions

Elizabeth Kubler-Ross, in her 1969 study with terminally ill patients, observed a step-like progression of their emotional experiences while confronting death. She reported denial, anger, bargaining, depression, and acceptance to be the stages (Berry & Zimmerman, 1983). A number of researchers extend this model to families with exceptional children (Berry & Zimmerman, 1983; Fortier & Wanlass, 1984; Opirhory & Peters, 1982). The major difference, according to Poznanski (1984) is that the exceptional child serves as a daily, physical reminder of the crisis. Therefore, the ultimate stage of acceptance may never occur (DeLuca & Salerno, 1984; Turnbull & Turnbull, 1986; Tuttle, 1986; Vernon, 1979). At this point it is important to discuss the different meanings of "acceptance of" and "adjustment to" a child's handicapping condition. Acceptance can only occur if the parent accepts both the child and the handicapping condition. Insomuch as the parent may accept both intellectually, he/she may never accept both emotionally (McClure & Lindsey, 1984). Adjustment refers to the process of "responding to the ever-changing demands in one's life, and as a result, is a life-long endeavor"

(Tuttle, 1986, p. 110). Tuttle (1986) does not believe there is an ultimate state of adjustment. "No sooner does one reach a state of equilibrium than some new event or condition requires attention, and disequilibrium is once again experienced" (p. 110). This is but one difficulty to applying the stage theory to families with special needs children.

There are other difficulties in applying the stage model to families with handicapped children. The parent's emotional reactions are not experienced in an orderly fashion (Tuttle, 1986), nor does each family member experience these reactions at concurrent times (Blacher, 1984). There are variations in behavioural characteristics, timing and duration of individual family member's reactions. Their responses may not readily fit into the stage model approach (Allen & Affleck, 1985). There is disagreement, also, "about the number of stages, the names of the stages, and the components of each stage" (Fortier & Wanlass, 1984, p. 17). In accordance with these observations, many professionals do not believe a stage model approach applies to families with exceptional children (Allen & Affleck, 1985; Blacher, 1984; Seligman, 1985).

One of the problems with applying a stage theory approach to families with exceptional children, is that

professionals may take the model too literally (Berry & Zimmerman, 1983; Blacher, 1984). They become concerned when a family skips a stage, or does not exhibit orderly emotional responses. The professional may respond by referring the family for unnecessary counselling (Lipsky, 1985). Seligman (1985) maintains that stages of emotional experiences should be considered flexible and changeable. According to Blacher, (1984), the question of whether sequential stages are fact or fiction when applied to families with exceptional children, remains to be determined.

One way of understanding parental response to raising exceptional children is through the stresses experienced, and their emotional manifestations. Through better understanding of these experiences, identification of positive coping behaviours may occur. In the following section, adjustment to and coping with an exceptional child is discussed.

Coping with Stress

Parents of handicapped children may experience lifelong adjustment and readjustment to their child's handicapping condition (Turnbull & Turnbull, 1986; Tuttle, 1986). One of the first principles for constructive and effective coping is the family's awareness of the irreversibility of the condition (Vernon, 1979). The

family must understand "the disability is not good, it is not bad, just a fact" (Diamond, 1981, p. 48).

A number of factors which influence parental adjustment are much the same as the variables which cause stress. The age of onset of the impairment, support of significant others, availability of professional services, and degree of impairment are variables which effect adjustment (Tuttle, 1986). As previously stated in the discussion of sources of stress, not all researchers agree to the conditions which cause stress, or affect the coping mechanisms.

The Webster New World Dictionary (1979) definition of "cope" is "to deal with problems, troubles, etc." (p. 110). Coping skills can be very demanding, difficult, erratic, and use much needed energy (Bristor, 1984; Tuttle, 1986). Similar to adjustment and stress, coping mechanisms are influenced by both alterable and unalterable variables. Perhaps the most prominant predictors of coping behaviour are the family's coping strategies used prior to diagnosis of their handicapped member (Bristor, 1984; Fortier & Wanlass, 1984). Other determinants of successful coping skills are the family's support systems, religious beliefs, ability to effectively share care-taking responsibilities, and their ability to make sense out of what has happened to them

(Bristor, 1984; Fortier & Wanlass, 1984; Longo & Bond, 1984).

The importance of understanding maternal coping, adjustment, and emotional experiences while raising a handicapped child can be summarized in a quote from Allen and Pearson's 1928 study of parental attitude towards their child's handicap.

> The child seems to adopt the same attitude to the disability that his parents do. If they worry about it, so does he. If they are ashamed of it, he will be sensitive also. If they regard it in an objective manner, he will accept it as fact and will not allow it to interfere with his adjustment (Harvey & Greenway, 1982, p. 357).

Thus it is important for researchers to develop an understanding of parental reaction to an exceptional child in the family. By providing early intervention strategies for parental adjustment, professionals will also be directly assisting the child.

Previous research, in parental experiences while raising exceptional children, has been primarily quantitatively based. A hypothesis was generally stated prior to the research and then proved or disproved, concluding the research. A different type of research, however, has been recently utilized when studying parents

of exceptional children. This research, qualitative in nature, applies the grounded-theory and will be discussed in the following section.

Use of Grounded Theory in Research

One type of research methodology is grounded-theory. Development of a theory, if possible, occurs after data has been collected and thematic analysis conducted (Bogdan & Biklen, 1982). Using this method, a theory is developed from the bottom or ground up. No judgements, preconceptions, or hypotheses are made prior to data collection (Glaser & Strauss, 1967).

Bogdan and Biklen's (1982) analogy of grounded-theory states:

> You are not putting together a puzzle, whose picture you already know. You are constructing a picture which takes shape as you collect and examine the parts. The process of data analysis is like a funnel; things are open at the beginning (or top) and more directed and specific at the bottom (p. 29).

Professionals may have difficulty applying theories, which have been based on clinical judegments, to families in non-clinical situations (Blacher, 1984). Parents attending clinical settings are generally referred because they are exhibiting negative psychological

behaviours. Theories based on research conducted in clinical settings may not always be generalizable to all parents of handicapped children.

Madiros (1985) contends the "interpretations of findings tend to be based on theoretical models that are not grounded in the experience of parents" (p. 26). Researchers must begin to base their theories in the context that gives meaning to the parent's responses. Morgan (1987), in her study of mothers with hearing impaired children, stated that mothers need to be studied through research which allows their personal experiences to be explored. Morgan (1987), and Adams (1987) both used a qualitative method to gather and analyze data concerning parental experience in raising exceptional children with hearing impairments and severe mental handicaps, respectively. Documented in both Morgan's (1987) and Adam's (1987) studies were concerns such as parent-professional relationships, educational needs, and support networks. Parent-professional problems included professionals in the medical, rehabilitational, and educational fields. Another concern cited by parents in these two studies was the education of their children. The educational concerns differed, however, according to the child's impairment. For example, the parents of hearing impaired children were concerned with communication

difficulties, while parents of children with severe handicaps were concerned with an education which was least restrictive, yet met their child's dependent handicap needs. While parent-professional relationships emerged as a concern for the parents in both of the studies, positive support from professionals was also mentioned. The support systems, whether professional, family, or friends, appeared to play an important part of coping with and adjusting to a child's exceptionality.

Summary of Literature Review

Research literature suggests that parenting special needs children is more difficult, stressful, and time consuming than parenting "typical" children. Care-taking responsibilities for a handicapped member of the family appear to be most demanding for the mother. These duties may, in turn, increase stress. For this reason, the mothers experience in raising the handicapped child is extremely important.

Sources of stress, and the emotional responses incurred, are important areas of research to develop an understanding of families with exceptional children. The parents, child, and professionals benefit when alterable stress variables are identified. Not only must these variables be identified, the positive coping strategies applied by parents must also be documented.

Some research questions arising from the literature review are as follows:

(1) What are the sources of problems, as indentified by the mothers, of parenting a visually impaired child?

(2) What, if any, emotional responses result from these situations?

(3) And, what coping behaviours do the mothers identify and utilize?

Focus of the Study

In order to report maternal experiences of raising a visually impaired child, data will be collected from an interview with the mothers as they discuss their experiences, as lived by them. "Any lived- experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describes (Van Manen, 1984, p. 21).

It is the intent of this research to describe the participants' perspective of their experiences raising a visually impaired child. Through the use of open-ended question interviews, and grounded-theory method, the maternal perspectives may best be documented.

Chapter III

Methods and Procedures

Statement of Problem

In this research project, the researcher was interested in the experiences of mothers with visually impaired children. Towards a more narrow focus, the interview questions were designed to answer questions concerning the problems and concerns, if any, of the participants, their emotional experiences, and strategies utilized in coping and adjustment to a family member with a visual impairment (see Appendix I).

Participants

Due to the low incidence of visual handicaps, and the utilization of grounded-theory method, random sampling was neither feasible, nor desirable.

Six mothers of visually impaired children were selected for this study. Criteria for selection of subjects were:

(1) The mother must have had a visually impaired child between the ages of 5 to 17 years of age.

(2) Mothers whose children have had only a single impairment (visual) were elgible.

(3) The child must have been registered as legally blind with the Canadian National Institute for the Blind, Alberta. Parental confirmation was sufficient for confirmation of this requirement.

During the past 4 years, the researcher has been

active in a local and provincial organization for the visually impaired. The mothers for this study were chosen through the researcher's association with that organization. The mothers need not have been active in, or involved with the society to participate. Insomuch as the research was to focus on maternal experiences documented outside a clinical situation, participants were selected from this parent organization, as opposed to the local, government agency for the blind.

The investigator openly explained the purpose, value, and relevance of the research prior to the individual's confirmation to participate. Informed consent (see Appendix II) and confidentiality were maintained throughout the study. If at any time, the parent(s) wished to withdraw themselves, or their research data from the study, they had the option to do so.

Prior to the interview session, each mother was asked to complete a demographic question sheet (see Appendix III) concerning her age, level of education, marital status, employment status, and the age and number of siblings in the family. All six mothers in this study were currently married. Their ages ranged from 25 to 55 years. Three of the mothers worked outside the home, in full or part-time positions. The level of education ranged from grade twelve diploma, to post

graduate education.

All of the families in the study had more than one child. The visually impaired children in the study birth orders were eith first born, or last born. None of the visually impaired children were in the middle birth order.

Data Collection

An open-ended question interview session was used to collect the necessary data. The interview questions (see Appendix I) were semi-structured in order to investigate the areas of interest. For example, the intent of question one was to probe the emotional issues for the mothers, during and after diagnosis of their child's visual impairment.

An open-ended question format interview session, according to Bradburn and Sudman (1979), is more appropriate for topics which parents may perceive as personal or threatening. Questions concerning emotional experiences and child rearing are personal in nature, and parents may view them as intrusive. The mothers were given the option of omitting questiongs they felt uncomfortable answering. The paren'ts level of trust and comfort with the investigator is vital to the accuracy of the data one receives (Turnbull & Turnbull, 1986).

The interview sessions were not so strictly structured so that parents could not deviate from the

discussion.

The interview sessions were held in the homes of the participants, whenever possible. Two of the interviews were conducted outside the parent's home, at their request. The initial interview was tape recorded and then transcribed onto computer disc for a written printout following the completion of the data collection. The interview sessions varied in duration. The shortest session lasted 45 minutes, with the longest session lasting 120 minutes. On average, the interview sessions continued for 90 minutes. Prior to the interview session the mother was given the option to omit any question she felt she could not, or did not want to answer. The tape recorder was then turned on, and the questions were asked in the identical order for each participant. During the interview, the researcher interacted with the mother through verbal acknowledgement of an answer, gestures such as nodding, and/or a question of clarification if needed. At the end of the session the mother was given a chance to expand or make reference to information she felt would benefit the research.

Upon completion of the results and discussion section of the thesis, the researcher noted that although the mothers discussed support networks, neither the father, nor the siblings were mentioned extensively in the

interview sessions. It was also noted that the word "stress" was not used by the mothers in their discussions of raising their exceptional child. To understand why these subject areas, fathers, siblings, and stress, were not mentioned in the interview sessions, it was felt a follow up telephone call should be made to each mother. The mothers were telephoned and asked two questions concerning the role of the fathers and siblings, and whether or not they felt raising a visually impaired child was stressful. The information obtained through this subsequent collection of data is included in the results section of the study.

Data Analysis

Upon completion of the final interview, a copy of the written transcript was printed from the computer file. Procedural steps for data analysis of written protocol, as outlined by Colaizzi (1978), were used.

The steps are paraphrased below:

(1) Read all of the participants transcribed interviews. Begin to acquire a feel for the data. Subjects descriptions are referred to as protocols.

(2) Return to the individual protocols and begin extracting phrases, words, or sentences that pertain to the phenomenon of interest.

Then, list these significant statements on a chart, or table.

(3) Now begin to formulate meanings. Try to extract meanings from each of the tables of significant meanings. This step must be conducted carefully, as the researcher is trying to go beyond the written transcript, but yet stay within it.

(4) Do step three for each protocol. Organize the aggregate formulated meanings into a **cluster of themes.**

(a) Refer back to the protocol to validate the cluster of themes. Check to see if there is anything contained in the original protocol which is not accounted for in the cluster of themes.

(b) This step will allow the researcher to decide if the themes contradict, or are unrelated to each other. At this point, one must refuse the temptation to prematurely generate themes, or ignore important themes.

(5) Step five is called **exhaustive description.** Now all the results are integrated into one description of the phenomenon.

(6) The researcher now tries to formulate the data of the investigated phenomenon into a statement describing the experiences of the participants.

(7) The final step is validation of the results. In order to validate the protocol analysis, the participant is asked to review the final written data (steps one through five of her own protocols). A single visit with the participant can accomplish the validation. The participant may add to, or negate any information she feels does not represent her perceived experience.

Instead of a personal visit to each mother, a letter was sent to the participants with a detailed account of their statements used in the thesis. The parents were then asked to telephone the researcher if there were any questions, concerns, omissions, or additions to their statements. Subsequently, the researcher telephoned each parent to ensure they received their statements and to ask if there were any problems. All six participants were satisfied with the information received, and were comfortable with the idea of receiving their data in written form, instead of a second home visit.

Chapter V

Results of the Study

The results of the study were classified into themes, as defined in Chapter I. As previously discussed, there were three dominant themes identified. The dominant themes were formulated from the semi-structured interview questions, which in turn, contained sub-themes which best described the phenomenon of the dominant them in greater detail. The following chart oultines the dominant themes, and subsequent sub-themes.

Dominant Theme 1 - Emotional Issues

Dominant Theme 2 - Coping Strategies

Sub-themes - (2a) Personality
- (2b) Child's Attitude
- (2c) Accomplishments
- (2d) Support Networks

Dominant Theme 3 - Problems & Concerns

Sub-themes - (3a) Professionals
- (3b) Education
- (3c) People's Attitudes
- (3d) Time Involvement

The discussion of the dominant themes, and sub-themes will appear in the order of outline which appears above.

The categorization of sub-themes within dominant themes is not absolute. While support groups were discussed as being a coping strategy, they were also described as a problem for some mothers. Thus, there was

some degree of overlap between sub- and dominant themes.

The names of the participants have been changed to ensure confidentiality and anonymity. Any specific details which may identify the participant have been altered or omitted from the text. So as not to identify individuals through inclusion of the child's gender, the term his/her or he/she will be used throughout Chapter V and VI.

For clarification, the interview questions will be given prior to the discussion of the relevant dominant theme.

Dominant Theme One- Emotional Issues

The question "What are your feelings and thoughts about your child's exceptionality? Please begin by explaining how you felt, if you can, after your child was diagnosed" was the first question of the interview session.

All six of the children in the study were congenitally visually impaired, however, not all were diagnosed at birth. Diagnosis time ranged from birth to six months of age. Although the diagnosis did not occur at birth for some children, each mother felt it necessary to discuss her child's exceptionality starting with the child's birth.

Each of the six mothers described events which occurred prior to and at birth. The mothers discussed

their normal pregnancies and deliveries. Their emotional feelings following diagnosis ranged from disappointment, disbelief, denial, anger and concern for the child. Two of the mothers interviewed had infants who were critically ill at birth. Although several of the children in this study were premature, the prematurity was not necessarily the cause for the visual impairment. In their experience, the idea of their child's congenital visual impairment was not as frightening as the medical problems which posed a threat to their child's immediate mortality. According to Sarah, ..."any parent's first inclination is to keep the child living, no matter what!" Their thoughts focused on maintaining the child's life, not the visual impairment which might develop due to the life-saving techniques used at the hospital.

Although Debbie's child was diagnosed six months following birth, she remembers her first reaction to the diagnosis as being disbelief. She did not have a "severe" reaction, Debbie recalls, and consequently the doctors were concerned with her lack of emotional response. Debbie denied the fact that there was nothing the doctors could do to save her child's vision, even though the physicians explained to her there was little or no hope. "I didn't rant and rave, though, I was in a state of disbelief, like denial." Cindy, too, discussed her emotional state upon

returning home from the hospital with her visually impaired infant.

> I kind of moaned and cried a lot the first couple of months after I found out that he/she was visually impaired. Then I decided not to, I knew it wasn't doing any good.

Although the mothers discussed their child's birth and diagnosis in detail, several stated there were periods during the diagnosis, or directly after diagnosis, they could not recall. Cindy believes she was in shock after the diagnosis, because she does not remember the conversation between her and the physician after he told her the baby was blind. One mother, Ann, was given the diagnosis while still in the recovery room.

> You read in books about people's reactions, they describe it like an explosion or something. I never really knew what that meant, until I had this happen. The whole room, the equipment and everything, seemed to explode and was spinning around. It was just like the whole world had fallen apart. I went to pieces then.

Arriving late to the hospital, Ann's husband had missed the delivery and diagnosis. In retrospect, she was grateful, however, to have her own initial reaction, alone, before facing others. She asked the doctor to

contact her husband, to give him the news, because she could not, nor did she want to tell anyone herself.

Ann also discussed the application of a stage model theory. In the course of the interview, she related a stage theory to her own experience of raising an exceptional child.

> I can't really say that you come to an acceptance stage. I am still reliving emotions that I had when he/she was little. Nor did I go through every emotion as described in the stages. There is not one day that goes by that I don't wish he/she were sighted. It may not have been better, but it would have been easier!

The six mothers' emotional reactions seemed to vary with their individual situations, and personalities. One mother stated that she was not as worried about her child's future when the child was an infant, as she is now that her child is in school. Several mothers still seemed bitter, or angry, at events which happened at the initial diagnosis, whereas other mothers, although stating it was a negative experience, have resolved some of their negative feelings. Although seemingly confusing, the mothers emotional experiences were similar, yet all very different. This is because while the mothers may have

experienced similar emotional reactions, the reactions varied in time of occurrence, and degree of severity.

The experiences described by the mothers seemed filled with strong feelings. Perhaps individual emotional labels were not applied to each experience, however, one sensed the anger, love, caring, disappointment, and conviction in the recollections of their stories. The quiver in their voices, the furrowed brows of anger, or a smile emitted while reflecting on their perserverance cannot be preserved on the tape recorder. These emotional clues can, however, be witnessed while discussing the parent's experience through a personal interview session.

The intitial diagnosis period was the major period in their lives which related to discussion of emotional issues. However, throughout the interview mothers discussed their anger at professionals, or the educational system, and/or worry over their child's future. They also discussed the excitement over their child's accomplishments, and happiness with their child's progress. Thus, not all emotional issues identified in this study were negative experiences.

Because the identification of emotional issues was interspersed throughout the sub-themes, the dominant themes may not be inclusive or concrete. Some issues, such as support groups, appeared to be a coping strategy for

some mothers, and a problem for others.

The next theme to be discussed is the coping strategies of the mothers. Although they did not always label these strategies as "coping mechanisms", the strategies they described appeared to be a factor in adjustment to and coping with their child's visual impairment.

Dominant Theme Two - Coping Strategies

The question related to this theme was:" In general, how do you approach problems? Can you describe what you do to make yourself feel better emotionally? How do you cope with the difficulties?" Several strategies stemmed from this question, however, strategies such as support groups were mentioned also when the mothers related to their problems. The first sub-theme to be discussed is that of the mother's personality.

Sub-theme - (2a) Mother's Personality

Several mothers stated that their personality, be it easy going or tough, aided them in dealing with problems. The sub-theme of personality was identified not only from the mother's comments on personalities, but also through the researcher's perception of the parent during the interview session. The personalities of these mothers appeared easy going, yet one sensed a serious conviction which enables them to deal with problems while raising a

visually impaired child.

The mothers stated that one must try to do the best one can, and to believe in oneself. They discussed periods of the child's life when they questioned their own ability to raise their exceptional child. According to Sarah:

> You get to a point when you can cope quite nicely and you think you're handling it well, and then you run into something and you're back to square one again.

However, Sarah contends that she has done the best that she can and felt that her child will succeed.

A mother's personality or attitude towards the situation may change as her child matures. For Kathy, this meant that:

> As time goes on, you get more used to it, that your kid is blind. You get angry more towards outside things, like school and people's attitudes. Not focusing on the fact that your kid is blind.

However, Kathy said, "years later it still tugs at you sometimes. I just don't dwell on the down times."

Dealing with your own feelings, and being aware of your own personality, appeared important in handling problems. "If you have a positive outlook, so will the child" states Debbie. She believes there can be a lot of

guilt derived from raising an exceptional child. Looking back on what you could have, or should have done, may cause additional guilt. The mothers agreed, however, that dwelling on negative aspects of raising an exceptional child does not change the situation, nor does it create any positive results.

Thus, the mothers' personalities appeared to be a factor (i.e. their ability to deal with problems as they arise) in their capability to cope and adjust to their child's visual impairment. One can speculate that one may assume the mothers' personalities and abilities to deal with problems affects the child's attitude and personality.

The second sub-theme of the dominant theme of coping strategies deals with the child's attitude and its effects on maternal coping.

Sub-Theme - (2b) Child's Attitude

During the course of the interviews, each of the six mothers referred to her child's positive attitude towards his/her blindness, and how her child's attitude has helped her to adjust to the visual impairment. The six mothers discussed how their children were happy, outgoing, and acted like normal children. Debbie believes that her child has "made the adjustments to it (visual impairment), and it has been more difficult for me!" Her

child is "willing to take hold of his/her life, and is not going to let this slow him/her down or hold him/her back." Ann says that her child is happy, and things pertaining to blindness are not a big deal to him/her. Ann stated that:

> When he/she was very young, he/she started helping us with our attitude. He/she has always been our biggest help towards adjusting to his/her blindness. The fact that he/she has never really been bitter has helped too.

A visual impairment appeared to be a burden moreso for the family than it did for the child. One mother, Kathy, said that her child "knows he/she is blind and that his/her eyes are different." Kathy's child handles his/her impairment very well, and has been taught that because he/she is blind "doesn't mean that he/she is not good, nor that he/she is limited in his/her abilities."

All six mothers spoke of their child's positive attitude towards his/her visual impairment. The child's positive attitude towards the visual impairment appeared to have an impact on the mothers adjustment to and acceptance (if possible) of the visual impairment. The problems and difficulties, as discussed later in dominant theme three, appeared to affect the parents more so than the child, even though some problems such as

Braille homework, were child related. The child's ability to maintain a positive attitude seemed to provide an appropriate example of positive thinking for the mothers.

In association with the child's positive attitude, the child's progress and accomplishments appeared to provide a positive step towards adjustment for the mothers.

The third sub-theme in the dominant theme of coping strategies deals with the child's accomplishments and progress.

Sub-theme - (2c) Child's Accomplishments

The mothers identified their child's accomplishments and progress as being a positive step towards adjustment. Several mothers spoke with pride about accomplishments, which professionals, both medical and educational, said their child would never achieve.

For Debbie and Betty, the idea that their children were maturing, progressing, and making positive strides to function normally, was beneficial. Through these accomplishments, Debbie has realized that "we have a handle on this thing now, we are going to be all right." She refers to the child's accomplishments as being a wonderful addition to raising a visually impaired child. These early accomplishments have also given Debbie hope for future endeavors.

Betty refers to her child as "behaving like any normal child would." She contends that her child is very "sociable, outgoing, and the fact that I have normal expectations for him/her" has helped. Betty also hoped that "as we go along we can always encourage him/her to do anything that doesn't limit his/her and his/her self-esteem."

Kathy and Debbie discussed the early intervention programs as being an important step towards their child's progress and development. Seeing their children progress has enabled them to have hope for the future. Progress of her child's abilities, according to Sarah, has been a positive experience because:

> It always amazed me that there were things he/she should be doing for himself/herself and I think he/she is not ready , but all of a sudden he/she decides he/she is ready and then accomplishes so much.

Progress and accomplishment appear to provide a positive step towards coping with and adjustment to the child's visual impairment. With each new accomplishment, the mothers seemed to be able to look forward to the future with some optimism. Not one of the mothers in this study claimed any credit for their child's accomplishments and progress. Any individual who has worked with a

visually impaired child knows, however, that progress and accomplishments come only with the dedication, commitment, and efforts of the parent(s) providing the early experiences. Their support and time involvement with the child has undoubtedly enabled the child to progress and succeed.

Support, whether for the child or the parents, comes from many different sources. The fourth sub-theme of the dominant theme coping strategies deals with the support networks and their effects on maternal coping.

Sub-theme -(2d) Support Networks

Support, be it financial or emotional, appeared to be an aid to coping with an exceptional family member. Support may come from family members, friends, parent groups, and/or organizations servicing exceptional individuals. The government organizations which serve the visually impaired often gave the mothers reading materials, suggestions, and moral support. Their services did not always allow them to provide the parents with one-to-one instruction. The mothers, however, spoke highly of the professionals who came when the parents requested home visits.

It is not surprising that parent support groups were mentioned in the interview sessions. Although not all of the mothers were currently involved with parental

support group, they have all been so in the past.

Meeting with other parents of visually impaired children, whether in a group or one-to-one, was extremely important for Sarah while her child was an infant. The parent group not only supported her with an advocacy role in her struggle with a school board, but also offered financial aid for special equipment which the school system would not, or could not purchase. She believes that many parents do not "...go the route of support groups..." and felt they were "...really missing the boat!" Her decision to meet with parents encountering similar experiences was a positive experience for Sarah. According to Betty, it is beneficial to become involved because "...whether I can help someone else, or they can help me is important." By attending support group meetings, the mothers realized they were not alone, and that there were parents who had the same problems as they had. "Even knowing that some people are worse off than you..." states Sarah, "...was beneficial."

According to Debbie, "...actually searching out people who deal with this situation all of the time, and getting involved with support groups ..." was invaluable to her. While Debbie agreed that support groups are important, she also experienced the negative aspect of joining a segregated group. For Debbie, it was attending

an annual social event which proved disasterous for her. Debbie shared her personal feeling of being uncomfortable around "totally blind" people. Debbie described her experience:

> I wasn't prepared to go to the party and face people who were totally blind. This was very difficult for me emotionally. I was feeling very threatened that this (total blindness) could happen to my child, and how was I going to cope with that. It stirred up a whole different set of emotional problems for me.

With some groups, says Kathy, you realize that the "only reason I know you (other parents) is because we both have blind kids." For her, the negative aspects of joining parent groups pertained to the parents who insisted upon comparing the progress of their visually impaired children. This comparison, contends Kathy, only begets additional stress and/or guilt that a parent does not need. Comparison of progress can occur, however, not only in support groups, but in individual parental interactions with friends. According to Ann, the comparison of the children's progress "...only nags at you. You begin to question your ability, and this in turn affects your self-confidence." The mothers stated that guilt sometimes is felt when they see what other children are doing, and they

realize what they should have, or could have been doing with their children. It appears, then, that parent groups can have both a positive and negative impact on coping.

Two of the mothers specifically discussed their involvement with the church, and how their religion played an important role in their ability to cope. The support from their ministers, congregation, and personal faith was encouraging.

Family support was mentioned by the mothers as being extremely important in their adjustment to their child's visual impairment. The fact that their families, both immediate and extended, were accepting of their child provided the mothers with encouragement. Their families did not make a "big issue" of the impairment, and treated the child as normal. It was comforting to Ann to see her family's acceptance of her child:

> My child had a lot of plastic surgery during his/her life, and sometimes he/she looked awful. But my family would always comment how gorgeous he/she was. That made me happy to know they too, could see past all of that, and see the beauty of this child.

Although negative aspects of support groups were discussed earlier, the mothers agreed that the positive apsects out-

weighed the negative. They stated that involvement with parental support groups and agencies for the visually impaired was important for themselves, the child, and the family. Support also came from extended family members, friends, and for some, professionals in the field of visual impairment. The types and amount of support the family receives has probably affected their ability to cope.

The four sub-themes discussed in the dominant theme of coping strategies were personality, child's attitude, child's accomplishments, and support networks. Discussion of coping strategies is important, as research has often dealt with the problems and difficulties parents face, without providing insight as to how they cope.

The next dominant theme deals with the problems and concerns the mothers encountered while raising their visually impaired child.

Dominant Theme Three - Problems and Concerns

The question which provided a focus on problems and concerns of raising a visually impaired child was: "In your opinion, what causes the most problems for you while raising your child?" This question needed little elaboration for the mothers. Although the mothers did not portray the raising of their exceptional child as negative, they all discussed problems and concerns.

One mother stated that she felt there were two types of problems she dealt with while raising a visually impaired child:

> There are the ones that are things like tackling the school board, the concrete sort of things. I think those are the kind of problems you can deal with, and be effective. I think other kinds of problems are the ones at home, that are more of an interpersonal, and emotional kind between family members. Those are the ones I have a hard time with.

It seemed appropriate to begin the discussion of problems with the parent-professional conflicts, as portrayed by the majority of mothers. This problem may be the first a mother encounters while raising a visually impaired child. The initial diagnosis only begins the continuous barage of professionals with which parents are faced with while raising their exceptional child.

Sub-theme -(3a) Professionals

The problem with professionals began for the majority of mothers when the child was diagnosed. For several mothers, the diagnosis consisted of the physician telling her that her child was blind. The doctor briskly left the room without offering guidance or condolence. This blunt statement of diagnosis, along with the lack of guidance,

made for a negative, unforgettable experience. Perhaps when the mothers needed support and guidance the most, it was not offered.

Kathy recalls the initial diagnosis:

> I remember the opthalmologist phoned me to go down to his office and I remember not wanting to go, because you know, you know what they are going to say. He said it straight out. He said that he/she will be blind. It was just short and sweet, and that was it. You can discharge your kid. No direction at all. Well, I got him/her home and thought, well, what do I do with this kid now?

Several mothers discussed the callous attitudes which some of the medical professionals portrayed towards them and their children. One mother, Cindy, was taken from the waiting room, where she was speaking with her husband and a friend, back to her hospital bed. There, alone but for other patients, she was told her child was blind. The doctor then proceeded to explain her child's condition in medical vocabulary which she could not comprehend. He then abrubtly left the room. Cindy says "I was not impressed. I was angry, and still am, at the pediatrician who told me." These mothers felt that there must be a better way to discuss a child's visual impairment, especially during the initial diagnosis.

According to Sarah, however, medical professionals' callousness does not stop after diagnosis. Throughout the child's life there will be numerous eye exams, sometimes two or three time a year. She complains that eye specialists do not take the time to sit down and explain your child's situation. Parents often leave a 2 hour exam without ever talking to the opthalmologist. Sarah contends that the child is treated "just like another eye." The doctor does not acknowledge her presence in the examination room, nor does he call her child by name. "He looks at the attending students and says "this is an interesting eye'". One experience Sarah recalled, was the extensive eye surgery her child needed:

> After the operation, the doctor never came down to tell us what happened. He had just told us prior to surgery the chance of losing the eye was great. When he/she (child) went into the operating room, we didn't know if he/she would come down with one or two eyes. When he/she (child) came back, the doctor did not come with him/her. We did not find out until later that night, at home, whether that child had an eye under that patch or not.

The majority of the mothers complained about the medical professionals. According to Cindy, "you feel like you are on an assembly line!" Debbie too, found visits to

the teaching clinic cold, impersonal, and always discouraging. "The hardest thing was that nobody would tell us what was going to happen to my child's vision."

Educational, as well as medical professionals, appeared to pose problems for some of the mothers. Often educational, and rehabilitational professionals would tell the mother not to expect too much of their child, or that the child would never progress to a certain level. The mothers felt that educational professionals often stereotyped visually impaired children, and did not take into consideration the amount of useful vision their child had. The fact that some of the professionals' suggestions did not pertain to their child, was confusing for the mothers. For example, mothers of low vision children were given suggestions and advice which pertained to children who were totally blind. Two of the mothers cautioned those parents who deify professionals. "Just because someone tells you something, don't always take it as gospel. You soon learn that not all suggestions apply to your child, and that you may have to do your own thing." This is true..." states one mother, because "...you are the one person that spends the most time with your child and best knows what he/she is capable of doing."

Not all experiences with medical and educational professionals were negative. According to Ann, it was the

caring medical staff in the hospital which lead her to believe she was not alone in this ordeal.

Perhaps it is due to the fact that parents of exceptional children must encounter so many medical, rehabilitational, and educational professionals during their child's years at home, that negative experiences exist. This does not, however, explain the mothers first and perhaps most difficult encounter during the initial diagnosis.

Professionals' attitudes, and their lack of interest, appeared to cause difficulties for the mothers in this study. The mothers felt as if they were treated like second class citizens when it came to their involvement with educational and medical interventions for the child. Respect between the parents and professionals was not mutual, stated several mothers. The fact that in the early years parents relied so heavily upon the professionals' attention and suggestions for their child, made it difficult for the mothers when conflict arose within the partnership. Whereas the parent-professional conflict appeared to be a very real problem for the majority of mothers, meeting the educational needs of their child was not only a problem, but a major concern.

Sub-theme - (3b) Education

According to the mothers in this study, educational

obstacles, whether funding or programming, appeared to cause constant struggles. Funding is a major concern for parents, as the equipment and the teacher aides for these children may cost the school district large sums of money. Two of the mothers stated they may have to become their child's aide at the school due to recent cutbacks in the system, and the lack of funding available since "block" funding was instituted in Alberta.

According to Debbie and Kathy, the educational endeavor is a constant struggle. Kathy states that her child is in grade (omitted) and "it's already World War III!" Debbie contends that the fight for proper education for her visually impaired child is a constant disruption in her life. She must meet many times with school board officials, principals, and teachers concerning her child's educational program.

Several mothers remembered when visually impaired children were sent to British Columbia, to the school for the blind, to be educated. The thought of their children leaving the province to be educated in B.C. was very traumatic. Because her child was allowed to stay in province, Ann didn't complain much about educational difficulties. The programs in Alberta, however, were pilot projects and Ann now sees the problems with the early programs.

> If I had things to do over again, I would as far as education goes. It was just that we never questioned it, and just accepted what people handed out.

All six of the mothers in this study had visually impaired children currently in school. The levels of education for these children ranged from kindergarten to junior high. One pessimistic view from the mothers' discussion on education, was that as the children grew older, educational difficulties increased. The visually impaired students in junior high school must contend with additional homework, social functions, and complexity of the courses offered. For example, one child was enrolled in geometry, a required course, which is primarily visual. The parent was concerned for her child's ability to cope in that type of class.

As much as educational and professional attitudes appeared to generate problems for these mothers, concerns with other people's attitudes, and time involvement also appeared to cause problems.

Sub-theme - (3c) People's Attitudes

One disturbing problem for these mothers seemed to be people's attitudes towards their children. Some mothers felt their children were discriminated against due to their impairment, while other mothers felt it was the rude

comments made in public that caused problems. Although the rude comments were disturbing, the mothers seemed understanding of the public's comments. Ann states that "...before I had my child I probably could have never looked at a child wearing prostheses." Sarah had similar feelings:

> When someone makes a nasty comment, or stares at him/her, I know that I would be that way too if I didn't have a blind child. That's the way you handle that attitude.

Several of the mothers described outings to shopping centers as being embarrassing. One mother said that she often tried to hide the fact that her child was blind. Debbie described shopping center incidents as being embarrassing for her:

> It was, well, he/she (child) was such a showpiece almost. And people were so pushy and curious. People couldn't believe that this little baby would have to wear glasses. They would come over and stare at him/her and ask me if the glasses were a joke.

Pushy, said Kathy, was an appropriate description of many people when it comes to their curiousity about visually impaired children.

> It really made me mad when people used to stare

> at him/her. I used to lip off the people who would do that. Then one day I realized that it was stupid, I can't stop it (staring). It's like when you are growing up, you are so curious and stare.

Kathy also felt that the hardest part about people's attitudes was their reluctance to accept her child "...as a normal, giving human being. "People..."contends Kathy, "...often assume he/she cannot do things for himself/herself and you get mad at that."

Sarah believes that attitudes will change with future generations due to integration. She remembered one experience she had with a neighbor shortly after she moved into her new home. The neighbor was "... one of those curious types." She asked Sarah if it would not have been better if her child had been retarded, than being blind. sarah believes that due to integration of exceptional children into the school systems, the next generation won't be so ignorant about handicaps. "Hopefully..." she states, "...kids won't think twice about him/her being blind, or retarded, or whatever, and just see them as kids."

Although the mothers seemed to be understanding of the public's attitudes towards their children, peoples' comments, attitudes, and reactions appeared to create

unneccessary stress for mothers. As Sarah stated, future generations, through the use of public education, may not view exceptional children as being so different.

In the discussion of the child's accomplishments and their effects on maternal coping, the point was made that parents often have given much of their time and efforts to see the child succeed. In the next sub-theme, in the dominant theme of problems and concerns, time involvement is discussed.

Sub-theme - (3d) Time Involvement

Whether the time involvement with their child was a source of stress for mothers was not clearly defined during the interviews. Time involvement, however, was mentioned by all of the mothers, and seemed to play an important role in the raising of a visually impaired child. Time involvement included the one - to - one instruction needed from infancy to provide hands-on experiences for the child, and learning of educational techniques such as Braille. Correcting bad habits, such as head drooping, also was time consuming for the mother. The mothers also noted that one- to- one instruction was extremely important, however, it was taxing and time consuming. Kathy discussed the process of hands-on application of teaching your visually impaired child:

Explaining things to her takes time and it

> takes it's toll. It is hard a lot of times to take time to explain things several times. It is easier to say "never mind" or "forget it" but you can't do that. It is always hard doing hand-on-hand things, you have to bring the experience to her.

The learning of Braille was identified as being time consuming for the child and the parents. Several mothers have taken extensive Braille courses in order to aid their child in his/her education. Time is spent practicing the child's Braille technique, or learning newly taught Braille lessons. School homework for their visually impaired children tended to last long into the evening. Even at grade one or two, the children had to come home and practice their Braille, or transcribe their homework. Cindy's child "had extra hours of homework every night, more than the other kids." That, she stated, was hard on her child, which in turn, made it difficult for the parents. She worried that the child was missing social activities that other children his/her age were participating in. Visually impaired children learning Braille, for the first time, often spend two or three days a week during their summer holidays with an instructor to maintain their Braille skills.

The time involvement of raising a visually impaired

child is not only taxing for the parents and the exceptional child, the siblings may suffer too. Debbie's sighted children had problems with the extra time and attention given to their visually impaired child. Debbie worries because:

> They all want the same amount of time and attention. He/she requires special attention and our daughter/son is very resentful and harbors a grudge against his/her visually impaired sibling. That causes a lot of stress for me.

Betty contends, however, that this special attention is a fact of life. Whenever possible, her family tries to provide special time for all the children. Sarah recalls spending an enormous amount of time with her visually impaired child as he/she was growing up. She had little time left to give to the other children in the family.

> Looking back, I wish that I had spent more time with the other children. Seeing how he/she (visually impaired child) is progressing, I think I missed the boat with the other kids. I was so involved with him/her. We certainly did not intend to be one sided though.

The time commitment included the amount of time spent with early intervention techniques, continual hands-on

experiences, and the learning of special educational techniques such as Braille. Athough the mothers agreed that time commitment is necessary and beneficial, it appeared to create difficulty for the entire family.

Summary of the Three Dominant Themes

The three dominant themes, with sub-themes included, are interrelated throughout the study. For example, when parental support groups were discussed, mothers classified them as having both helpful and harmful effects. Interrelated also, were the minor themes of personality, child's attitude, and child's accomplishments. It is difficult to say which variable precedes which. The mother's personality may be the driving force in the development of the child's positive attitude. The effects may be, in turn, reversed to say the child's attitude affects the mother's personality and ability to cope with problems. One cannot, therefore, discuss each theme as an individual entity, without relating the results to each of the interrelated major and minor themes.

The three questions used for the initial interview session were successful, in the researcher's opinion, in gaining information concerning problems and concerns, emotional issues, and coping strategies.

There were, however, two additional questions which emerged from the results of the study (as mentioned in the

methods section). The fact that the word "stress" and fathers and siblings were not mentioned in the interview session raised two questions. "Did the mothers feel that raising a visually impaired child was stressful?" and "what was the role of the father and siblings."

The mothers felt as if parenting a visually impaired child was stressful, even though they did not mention the word "stress" during the interview. Stress was not mentioned, according to one mother, because stress is in our everyday life, and you become accustomed to it. The mothers agreed that although situations may be stressful, they are not always labeled as such. The role of the father and siblings, according to the mothers, has been very supportive. The mothers also believed, in their opinions, that the fathers and siblings have adjusted well to the situation.

A discussion of the results follows, comparing and contrasting the results with the findings in the literature review.

Chapter V

Discussion

In the discussion section, the results will be compared and contrasted to the information presented in the literature review. Included in the discussion are the problems and concerns, the coping strategies, the relation between two similar studies, factors effecting stress, and the subsequent follow up data collection on stress and fathers and siblings.

Problems and Concerns

In the result section of thes study, it appeared that parent/professional relationships posed problems for the mothers. Similar results, concerning professional relationships, were found in Adams (1987) study of parents with dependent handicapped children, and Morgan's (1987) study of parents with hearing impaired children. Perhaps the fact that parents with exceptional children are continuously involved with professional personnel explains the difficulties faced. As cited in the literature review, parents often felt that professionals did not understand or have empathy with their situation (Garguiolo, 1985; Lipsky, 1985; Turnbull & Turnbull, 1986). The literature also indicated that parents perceived professionals to be negative, unavailable, and condescending. The major concerns portrayed in the literature review concerning the parent-professional partnership, were apparent in the conversations with the mothers in this study.

Education of their visually impaired children was another concern/problem for the mothers in this study. Whether they worry about appropriate programs, funding, or equipment, the parent of a visually impaired child seemed to be concerned about the child's educational needs. Although educational concerns were not discussed in the literature reviewed for this study, Gallagher, et al., (1983) briefly mentioned the parental problems in dealing with their child's special programs. It was not stated, however, if these special programs included both early intervention and school programs.

Time involvement appeared to be another concern for parents in this study. Adams (1987) referred to time involvement as "commitment". Depending on the exceptionality, time involvement would vary. For the parent of a visually impaired child, one- to- one instruction providing hands-on experience, visits to medical and educational professionals, and the special duties such as learning Braille, were identified as variables which necessitate time commitment.

Coping Strategies

Variables which appeared to affect the mother's ability to cope with and adjust to the child's impairment included her personality, the child's attitude towards his/her impairment, the child's accomplishments and

support networks. Although the mothers did not frequently use the word "cope", they did suggest that these variables were the cause of their ability to handle situations which arose. The mother's personality may be one of the most important factors to adjustment, stated Gallagher, et al., (1983), and Bradshaw & Lawton (1978). Her personality may affect the child's attitude and ability to succeed. As previously noted, the mothers in this study did not take credit for their child's accomplishments. Bennett (1986) stated, however, that one positive side of parenting an exceptional child is that you can take credit for the majority of progress your child makes. The child's development is often dependent upon the parent's efforts and care. It is important, stated Bennett (1986), that parents realize that perhaps they have done the best they can with their children. Parents must be able to assess, their child's potential and realize that "your judgement is based on more knowledge than anyone else has." (p. 52).

The mothers in this study appeared to be coping successfully. This is not unusual, stated Longo and Bond (1984), for families with special children. Although past research tends to indicate that families with exceptional children have great difficulty in coping with the problems, families with exceptional children are often very functional (Kazak & Marvin, 1984). The family appears

to be able to change as the child develops. Adaptation and adjustment tends to be a lifelong process (Seligman, 1985).

At this point in the discussion, the relationship between this study and two studies recently conducted will be examined.

Comparison of Two Related Studies

Recently, two theses were completed at the University of Alberta, Edmonton, concerning the parental experiences of raising exceptional children. Morgan, (1987), focused her study on the experience of mothers of hearing impaired children. Adams, (1987), documented the experiences of parents with dependent handicapped children. These two studies were conducted using similar research methodology, as mentioned in Chapter I, the review of the literature.

It would be impossible to determine or suggest which parental experience appeared more stressful or difficult, as the three studies did not administer stress quantifying tests. The purpose of this section is, however, to discuss the similarities between the results of the three theses.

Parent-professional relationships were discussed in all three research papers. Discussion of negative experiences in the parent-professional partnership was documented in both Morgan's (1987) and Adam's (1987) theses. Adams (1987) stated that parents expressed strong

feelings about their relationships with professionals and social agencies. Although the comments ranged from very negative to very positive, the majority of comments made were negative in nature (Adams, 1987). The parents in all three studies often felt that professionals did not give them enough credit, where their child was concerned. The difficulties cited with professionals ranged across medical, rehabilitational, and educational agencies.

Education of their children appeared to be another concern of the parents in the three studies. The educational concerns varied, however, according to the disability of the child. For example, the parents of a visually impaired child may be concerned with the special equipment needed for a successful education, whereas the parent of a hearing impaired student may be concerned with the communication style used in the school. The basic concern of the parents in the three studies, was to have their child educated in the best, and least restrictive manner possible.

Support, whether from professional organizations or family members, was discussed in detail in Morgan's (1987) study and in this study. Although Adams'(1987) study did not include a section on support systems, the topic was discussed briefly in the section on positive professional relationships. The support systems varied for each parent,

in the individual studies, and across the three studies. Discussion of common supports, such as support groups and family members, was included in the study by Morgan (1987). The use of these various support systems was, however, mentioned in all three theses.

The three exceptionalities discussed in the theses, visual impairment, severe handicaps, and hearing impairment, appear to create similar concerns or problems for parents. The cause for these problems and concerns, however, may be strictly related to the child's exceptionality. As stated in the literature review, different disabilities create varied and unique situations. It would be difficult to say which group of parents experienced the greatest amount of stress and difficulty in raising their exceptional child. Even within the three groups, parents appeared to be experiencing different amounts of stress, and their abilities to cope with stress seemed to vary, also.

Stress- Related Variables

The questions asked during the initial interviews, deliberately did not contain the word stress, to avoid overly influencing the results. It was surprising, however, that mothers did not refer to the word stress during their interviews. Only one mother referred to her experiences as being "highly stressful." Whether these

mothers experienced stress or not, the situations described were certainly stress provoking, in the opinion of the researcher. Another aspect which did not emanate from the initial interview session, was the role of the father and siblings, and how they have been affected by the situation. To obtain this information, a telephone call to the mothers was placed after the completion of the result section of the study. The researcher was interested in why the fathers and siblings were not mentioned, especially when support systems were discussed. The findings of the telephone conversations, and reference to the literature review are as follows.

The first question asked concerned stress. Did the mothers feel there was stress involved in raising their visually impaired child? Yes, all six stated, there definitely was a considerable amount of stress involved. Why then, it was asked, was the word "stress" not mentioned in the initial interview session? In Betty's opinion:

> Maybe we didn't mention the "word" stress, but look at the comments about anger, frustration, concern, or worry. Those are all adjectives which relate to stress. In our family, we don't normally talk about stress. We do talk about problems like education, which is

stressful, but we don't label it as stress. Ann said "you carry on, you don't stop to think "this is stressful", it is your life, and that's the way it is." At one point, Ann experienced a delayed reaction to stress. All year she had been extremely busy with her child, and had not noticed herself becoming tired and worn down.

> I guess you get so wound up in things that you don't realize how tired you are, until you stop. But all the stress doesn't mean you can't cope. It is your life, you accept that about your life, and you don't stop to think about it.

Another reason for the word "stress" not being mentioned, said Kathy, was that "maybe people don't want to admit it, that's why it wasn't mentioned in the first interview, but there is a lot of stress involved."

Sarah's interpretation of why she didn't discuss stress, was "we don't think of it as stress." She felt that perhaps frustration may be a better word to use. Sarah also believes that although her life is stressful, she "can't lay it on his/her (visually impaired child) shoulders." Sarah contends that she has always been a worrier.

> I am that type of person who always worries, no

matter what. It's got a lot to do with my personality. I am that type of person, that is the way I am. I was this way before he/she was born, and would be this way, perhaps, if he/she weren't visually impaired.

In the literature review, certain variables causing stress were discussed. One type was linked to stress caused by child related variables. In this study, several child related variables pertained to the type of impairment (e.g. Braille, head drooping problems), the age of the child (e.g. education became harder as the child matured), the child's personality (e.g. attitude towards blindness), and the child's progress and accomplishments. Educational considerations appeared to be a stress evoking problem for the parents. Although stress related to educational concerns was not consistently cited in the literature, Gallagher, et al., (1983) mentioned stress resulting from the "special programs" which exceptional children attend.

Several variables which were listed as stress evoking in the literature review were not mentioned by the parents in this study. The parents did not mention their socio-economic status, occupations, number of siblings, and past experiences as variables which caused stress. Whether they were simply not mentioned, or were not a factor, was not

clear.

For the six mothers, stress was a definite consequence of raising a visually impaired child. The stress, they felt, was related to the situations cited in the dominant theme of problems and concerns. However, as one mother stated, "you don't have time to stop and say "this is stressful". As Ann stated, "you can't speculate how things would have been, you just know how they are now." Stress is present, it is real for these mothers, but they don't appear to dwell on the matter. Adams (1987) found too, in his thesis concerning parents of dependent handicapped children, that "parents tended to talk about the circumstances creating stress in their lives, rather than the stress itself." (p. 92).

The second question asked during the telephone conversation dealt with the fathers role in raising the visually impaired child, and the effects on both the father and the siblings. When the mothers were asked to define the fathers role, they stated that their husbands had all been "very supportive". For the majority of mothers, however, the chores and responsibilities associated with raising their visually impaired child were primarily theirs. One mother, Ann, felt that she and her husband shared the work equally. On the other hand, Sarah stated that her husband was from "the old school" meaning

the wives do most of the child related work. It did not appear to matter whether the mother worked outside the home or not. For two of the three mothers who did work outside the home, care-giving responsibilities were still primarily theirs. Although their husbands were supportive, the mothers felt as if they were responsible for the "day to day" activities concerning their visually impaired child. Several mothers commented that when "they needed a break, or to get away" the father would step in and take care of the child. But for Kathy, when it "comes down to his/her educational needs, and attending support group functions, I deal with that."

Father and Siblings' Reactions

In the second part of the question, the mothers were asked how, if at all, were their husband and siblings affected by the situation. Five of the mothers stated that their husbands handled the situation well, and did not seem negatively effected. One mother, however, stated that her husband went through a six week period, after diagnosis, where he would not talk about the situation. During the six weeks, Debbie's husband would not let her discuss the child's visual impairment with him. Debbie's husband could not be supportive to her during this time, as he was experiencing denial and could not deal with his own problems. Accordihg to the majority of mothers,

however, in their opinion, the fathers appeared to adjust well to the situation.

How, then, were the siblings effected by the situation of growing up with a visually impaired brother/sister? Only one mother appeared to have a deep concern for one of the siblings in her family. For this child, dealing with the time and attention the visually impaired child received was a constant struggle. This struggle, in turn, created stress for the entire family. Although only one mother referred to sibling problems, the other five mothers did suggest that the time involvement with their visually impaired child may be frustrating for the other children in the family. Ann was not sure if the problems faced by siblings in the family were related to the exceptional child.

> One of our children did express some frustration that the visually impaired child received more attention. This might have been because he/she was the middle child. That often happens with middle born children, they often feel left out.

Ann was not convinced that this child's frustration was related to the one child's exceptionality. She said that the siblings in the family had all been "great" with him/her, and that through their involvement, had played a positive role in their visually impaired child's early

development.

The comments made by the mothers concerning the adjustment of their husband and other children, were, in fact, their opinion. This does not mean that the fathers did not experience similar or just as serious emotional reactions as did the mothers. These comments were the mothers perspective of the situation. The siblings and fathers may have a different story to tell.

Due to the focus of the maternal perspective of raising a visually impaired child, the review of the literature did not discuss, in depth, the position of the fathers and siblings. However, it was suggested that future study in these two areas was greatly needed.

Although fathers of exceptional children have not been studied to any great extent, there has been some research concerning their role in the situation. According to Gallagher, et al., (1983) "fathers need to be more involved in programs for their children and need to be given the opportunity to express their frustration and anger." (p. 13). Fathers of exceptional children often tend to isolate themselves from home, according to Poznanski (1984). Thus, they may not have the opportunity or desire to discuss and express their feelings concerning the exceptional child. Poznanski (1984) also contends that it is not unusual for parents "direct most of the energy

and attention to the exceptional child, to the exclusion of the rest of the children." (p. 218).

It is clear, from the lack of literature concerning fathers and siblings of the handicapped, that future research should be conducted in this area, as well as other areas of concern.

The next section will discuss how the results of this study can be applied to future research. Noted also, will be the limitations and difficulties of this research study.

In summary, it appeared that parents do experience stressful situations although they do not necessarily label them as "stress." The major concerns discussed by the mothers included the parent-professional relationship, education, people's attitudes, and time involvement. The major coping mechanisms appeared to be the mother's personality, the child's attitude and accomplishments, and the support networks utilized by the family. It did not appear, according to the mothers, that the father and siblings were experiencing any extreme amount of maladjustment due to the visually impaired member of the family.

Chapter VII

Implications for Future Research

The discussion of limitations of this study relates to the generalization of results, the reliance on perceived experiences, and difficulties in replicating this study.

Although the content of the participant's interviews represnts their perceived experiences, there are several reasons why the results cannot be generalized to all mothers with visually impaired children. Firstly, the participants were, or have been, affiliated with a local parent support and advocacy group for the visually impaired. Parents involved with such groups may not be average parents with a visually impaired child. Becoming involved with support groups requires additional time of the parents. Not all parents are willing to spend their time, in conjunction with the time involvement of raising the child, with a support group. The mother's perceived experiences may not be the same as mothers who have not sought the support or guidance that these groups can offer.

Secondly, participants in this study were all white, married, and generally middle class mothers. There was a mix of rural and city dwellers, however, all participants lived in Alberta. The government agencies which provided services to the families were the same for the rural and city participants; the educational systems, however, were

not. Trying to generalize the results to inner city, ethnic, or low income families would not be feasible.

Thirdly, the researcher knew the participants prior to the study, an individual unfamiliar to these parents may obtain different results. It was because the researcher and participant knew each other, and felt comfortable with each other, that the researcher believed the data to be valid. Turnbull and Turnbull (1986) stated that the parent's level of trust and comfort with the investigator are vital to the accuracy of the data one receives.

Fourthly, reliance upon perceived experiences for data collection can limit a research study. For example, the researcher may ask the participant to describe an experience which occurred many years before. The participant's perceived experience may have changed over the years. The experience may seem less intimidating now than it did ten years ago. Although a researcher has no control over this, one should bear this possibility in mind. According to Bogdan and Biklen (1981), however,

> By learning the perspectives of the participants, qualitative research illuminates the inner dynamics of situations- dynamics that are often invisible to the outsider. (p. 30).

Therefore, the results one obtains through an interview session requiring the participant to discuss perceived

lived-experiences may have limitations, but it still provides the researcher with information which may not be obtained through mailed surveys or questionnaires. Surveys generally tend to be closed-ended questions which individuals may take little time in completing (Bradburn & Sudman, 1979). It may be difficult to inquire about personal experiences, such as the emotional reactions following diagnosis of an exceptional child, in a closed-ended question format.

Finally, a small number of participants were used in this study. Different results, or varied results may have occurred if a larger number (e.g. fifty or one hundred) of mothers were interviewed for this study. There too, was not a "normal" (i.e. mothers of sighted children) control group, used for comparison of experiences, in this study.

Implications for furture research, as well as application of the results towards prevention and intervention of perceived problems, will be discussed in the following section.

Implications for Future Research

It appears from the results of this study, that parents with visually impaired children contend with specific problems related to their child's impairment. Research and consideration are needed in the areas of support networks, education, and the relationship between

parents and professionals.

The parent/professional relationship has not always been successful for many of the participants in this study. Perhaps a greater emphasis on this relationship should be included in the training of medical and educational professionals dealing with parents. One preventive measure to be taken could be to supply materials concerning local agencies for the visually impaired, to physicians and opthalmologists working with parents of newly diagnosed visually impaired children. This would at least supply the parents with some information and guidance if the physician does not provide it verbally.

Meeting educational needs of visually impaired children should be an important goal of educators. Although programs are provided for the visually impaired, the majority of mothers stated that meeting their child's educational needs frequently occurs only after battles have taken place. Educating their child in an appropriate program appears to be a struggle for most of these parents. Educating a visually impaired child can be expensive, due to the cost of teacher aides and equipment, and school boards are not always open to negotions on these subjects.

While it was not the intention of this research to

test the appropriateness of a stage theory, it should be noted that no one parent related her experience to a stage-like progression of emotional experiences. One mother, in fact, disputed the stage-like progression, and did not feel it applied to parents withe exceptional children. This statement makes for possibly interesting future research in the area of stage theory and parents of exceptional children.

As discussed in the review of the literature, variables which affect the mothers' stress and adjustment to their child's impairment may be alterable or unalterable. It is difficult to say which of the variables discussed in this study can be altered. Attempts to alter, for example, people's attitudes towards blindness is progressing through educational information of exceptional children, and integration. Goals of a more positive parent-professional relationship, easing the educational difficulties, and providing support networks for parents should be considered for future development.

Research on coping mechanisms of parents could provide professionals with strategies to assist parents in coping with their child's exceptionality. Early intervention techniques and assistance, directly following diagnosis, would prove beneficial to parents who need coping strategies. Understanding, and providing for

parents emotional needs, would be beneficial for the entire family.

Research in the area of parenting visually impaired children is limited. There is a greater need to understand the lived-experiences of these parents. Understanding the effects of the exceptional child upon other family members, such as the father and siblings, would be of importance also. Each of the problem areas discussed, parent/professional relationships, education, people's attitudes, and time involvement should be studied for a better understanding of the difficulties faced by these parents.

In summary, perhaps the most important aspect of understanding parental experiences is to help professionals develop empathy towards, and provide quality services for families with exceptional children. Improvement of services such as support networks, early intervention techniques, and appropriate programs for both parent and child would aid in the understanding of families with visually impaired children, and indeed, all exceptional children.

REFERENCES

Adams, B. (1987) Sorrow or Committment; A Phenomenological study of the experience of being the parents of a dependent handicapped child. Unpublished Thesis. University of Alberta, Edmonton, Alberta.

Allen, D., & Affleck, G. (1985). Are we sterotyping parents? A postscript to Blacher. Mental Retardation, 24, 200-202.

Bachor, D., & Crealock, C. (1986) Instructional Strategies for Students with Special Needs. Scarborough, Ontario: Prentice-Hall Canada, Inc.

Beckman, P. (1983). Influences of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficeincy, 88, 150-156.

Beckman-Bell, P. (1981). Child-related stress in families of handicapped children. Topics in Early Childhood Special Education, 1, 45-53.

Bennett, C. (1986). Parenting a special child: How difficult is it? The Exceptional Parent, 16, 50-52.

Berry, J., & Zimmerman, W. (1983). The stage model revisited. Rehabilitation Literature, 44, 275-277.

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? Mental Retardation, 22, 55-68.

Bogdan, R., & Biklen, S. (1982). Qualitative Research for Education. Boston, Mass; Allyn & Bacon, Inc.

Bradburn, N., & Sudman, S. (1979). Improving Interview Method and Questionnaire Design. San Francisco, Ca: Jossey-Bass, Inc.

Bradshaw, J., & Lawton, D. (1978). Tracing the causes of stress in families with handicapped children. British Journal of Social Work, 8, 181-191.

Bristor, M. (1984). The birth of a handicapped child: A wholistic model for grieving. Family Relations, 33, 25-32.

Colaizzi, P. (1978). Psychological research as the Phenomenologist Views It.(p.48-71).In R. Valle & M. King (Eds.), Existential-Phenomenological Alternatives for Psychology, (pg. 48-71).

DeLuca, K., & Salerno, S. (1984). Helping professionals connect with families with handicapped children. Springfield, Ill: Charles Thomas Publishing.

Diamond, S. (1981). Growing up with parents of a handicapped child: A handicapped person's perspective. In J. Paul (Ed.), Understanding and Working with Parents of Children with Special Needs, (pg.23-50). Toronto, Ontario: Holt, Rinehart, Winston.

Ende, M. (1972). Three congenitally blind infants and their mothers. American Journal of Maternal Child

Nursing, 77, 55-65.

Ferguson, N., & Watt, J. (1980). The mothers of children with special educational needs. Scottish Education Review, 12, 21-31.

Fewell, R., & Vadasy, P. (1986). Families of Handicapped Children, Austin Texas: Pro-Ed.

Fortier, L, & Wanlass, R. (1984). Family crisis following the diagnosis of a handicapped child. Family Relations, 33, 13-24.

Fotheringham, J., & Creal, D. (1974). Handicapped children and handicapped families. International Review of Education, 20, 355-373.

Gallagher, J., Beckman, P., & Cross, A. (1983). Families of handicapped children: Sources of stress and its amerlioration. Exceptional Children, 50, 10-19.

Garguiolo, R. (1985). Working with parents of exceptional children, Boston, Mass: Houghton Mifflin Company.

Glaser, B., & Strauss, A. (1967). The Discovery of Grounded Theory, Chicago, Ill: Allyn & Bacon, Inc.

Hardman, M., Drew, C., & Egan, M. (1984). Human Exceptionality: Society, School, and Family. Boston, Mass: Allyn & Bacon, Inc.

Harvey, D., & Greenway, P. (1982). How parents attitudes and emotional reactions affect their handicapped child's self-concept. Psychological Medicine, 12,

357-370.

Heward, W., Dardig, J., & Rossett, A. (1979) Working with Parents of Handicapped Children. Columbus, Ohio: Charles Merrill Publishing.

Kazak, A., & Marvin, R. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33, 67-77.

Lipsky, D. (1985). A parental perspective on stress and coping. American Orthopsychiatric, 55, 614-617.

Longo, d., & Bond, L. (1984). Families of the handicapped child: Research and practice. Family Relations, 33, 57-65.

MacKeith, R. (1973). The Feelings and Behaviours of Parents of Handicapped Children. Developmental Medicine and Child Neurology, 15, 524-527.

Madiros, M. (1985). Role alternatives of female parents having children with disabilities. Canada's Mental Health, 24-26.

McClure, S., & Lindsey, J. (1984). A road to "Somewhere" for parents of severely handicapped children. The Pointer, 29, 32-37.

Mercer, R. (1974). Mother's responses to their infants with defects. Nursing Research, 23, 133-137.

Morgan, M. (1987) The Experiences of Mothers of Hearing Impaired Adolescents. Unpublished Thesis.

University of Alberta, Edmonton, Alberta.

Mori, A. (1983). Families of children with Special Needs. Rockville, Md: Aspen Publishing.

Opirhory, G., & Peters, G. (1982) Counselling intervention strategies for families with the less than perfect newborn. The Personnel and Guidance Journal, 60, 451-455.

Paul, J. (1981). Understanding and Working with Parents of Children with Special Needs. Toronto, Ontario: Holt, Rinehart, and Winston.

Poznanski, E. (1984). Emotional issues in raising handicapped children. Rehabilitation Literature, 45, 214-219.

Seligman, M. (1985). Handicapped children and their families. Journal of Counselling and Development, 64, 274-277.

Schulz, P. (1981). The parent-professional conflict. In A. Turnbull and R. Turnbull (Eds.) Parents Speak Out. (pg. 28-37). Columbus, Ohio: Merrill Publishing.

Simeonsson, R., & Simeonsson, N. (1981) Parenting handicapped children: Psychological aspects. In J. Paul (Ed.) Understanding and Working with Parents of Children with Special Needs. (pg. 51-88). Toronto, Ontario: Holt, Rinehart, and Winston.

Sobsey, D. (1987) Bill 59: Is this the End of Universal

Education in Alberta? University of Alberta, Education Psychology Department, Edmonton, Alberta.

Swick, K. (1984). Understanding special needs families. Journal of Instructional Psychology, 11, 37-46.

Turnbull, A., & Turnbull, R. (1986) Families, Professionals, and Exceptionality: A Special Partnership. Columbus, Ohio: Merrill Publishing.

Tuttle, D. (1986). Family members responding to a visual impairment. Edcuation of the Visually Handicapped, 18, 107-116.

Van Hasselt, V., Hersen, M., Moor, L., & Simon, J. (1986). Assessment and treatment of families with visually handicapped children: A project description. Journal of Visual Impairment and Blindness, 80, 633-635.

Van Manen, M. (1984). "Doing" Phenomenological Research and Writing: An Introducation. Monograph (7), University of Alberta, Edmonton, Alberta: The Department of Secondary Education.

Vernon, M. (1979). Parental reactions to birth defective children. Post Graduate Medicine, 65, 183-189.

Waisbren, S. (1980). Parents reactions after the birth of a developmentally disabled child. American Journal of Mental Deficeincy, 84, 345-351.

Webster's New World Dictionary, (1979) pg. 110, New York, New York: Simon and Schuster Publishing.

APPENDIX I

What are your feelings and thoughts about your child's exceptionality? Please begin by explaining how you felt, if you can, after your child was diagnosed?

(ask when child was diagnosed if not given)

(expand on points of interest, or ask for clarification if needed)

In your opinion, what causes the most problems for you while raising _____? What are the hardest
child's name
problems you face, whether over long periods of time, or daily difficulties?

- (elaborate on points of interest, ask parent to give more detail, if necessary)

In general, how do you approach problems? Can you describe to me what you do to make yourself feel better emotionally? What do you do, to cope with the difficulties, if any, while raising your child?

Looking back over your life so far with _____, what has been the best time for you? What has been the most difficult?

APPENDIX II

I,_____,agree to participate in this parent-interview project by Kimberly Hancock, for her M.Ed. thesis, under the supervision of Dr. Linda McDonald and Dr. Lorraine Wilgosh.

I understand the interview will be taped and the tapes erased when the project is completed to guarantee anonymity and confidentiality of my name, residence, and personal opinions. Certain details (family size, marital status, number of children) will be changed if necessary to insure anonymity.

I understand that I will be given a written copy of the final data discussing my personal experiences. At that time I am allowed to add to, change, or take out any information I feel does not represent my experience.I will only be allowed to view my personal data, and not that of the other participants.

_____

Signature of Parent

_____ _____

Signature of Researcher Date

APPENDIX III

DEMOGRAPHIC DATA SHEET

Name: _____ Code: _____

Address: _____

Telephone: _____ Age: _____

Level of Education: (please specify): _____

Marital Status: Single ___; Married ___; Divorced ___;

Other _____; _____.

If divorced or seperated, do you have custody of the visually impaired child? _____

Total Number of Children _____ Ages of Children

_____

Do you work outside the home: Yes ___(full-time___part-time___)

No ___

What groups, if any, are you and your family invovled in concerning visual impairments? _____

_____

Are you the birth mother of the visually impaired child?

_____